

University of Groningen

Secondary health conditions and quality of life in persons living with spinal cord injury for at least ten years

Adriaansen, Jacinthe J. E.; Ruijs, Laura E. M.; van Koppenhagen, Casper F.; van Asbeck, Floris W. A.; Snoek, Govert J.; van Kuppevelt, Dirk; Visser-Meily, Johanna M. A.; Post, Marcel W. M.; ALLRISC

Published in:
Journal of Rehabilitation Medicine

DOI:
[10.2340/16501977-2166](https://doi.org/10.2340/16501977-2166)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2016

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Adriaansen, J. J. E., Ruijs, L. E. M., van Koppenhagen, C. F., van Asbeck, F. W. A., Snoek, G. J., van Kuppevelt, D., Visser-Meily, J. M. A., Post, M. W. M., & ALLRISC (2016). Secondary health conditions and quality of life in persons living with spinal cord injury for at least ten years. *Journal of Rehabilitation Medicine*, 48(10), 853-860. <https://doi.org/10.2340/16501977-2166>

Copyright

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

Take-down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

ORIGINAL REPORT

SECONDARY HEALTH CONDITIONS AND QUALITY OF LIFE IN PERSONS LIVING WITH SPINAL CORD INJURY FOR AT LEAST TEN YEARS

Jacinthe J. E. Adriaansen, MD, PhD¹, Laura E. M. Ruijs, MSc², Casper F. van Koppenhagen, MD, PhD³, Floris W. A. van Asbeck, MD, PhD², Govert J. Snoek, MD, PhD⁴, Dirk van Kuppevelt, MD⁵, ALLRISC*, Johanna M. A. Visser-Meily, MD, PhD¹ and Marcel W. M. Post, PhD^{1,6}

From the ¹Brain Center Rudolf Magnus and Center of Excellence in Rehabilitation Medicine, De Hoogstraat Rehabilitation and University Medical Center Utrecht, ²Center of Excellence in Rehabilitation Medicine, ³Department of Rehabilitation Medicine, Nursing Sciences and Sports, University Medical Center Utrecht, Utrecht, ⁴Rehabilitation Centre Het Roessingh, Enschede, ⁵Rehabilitation Centre Sint Maartenskliniek, Nijmegen and ⁶University of Groningen, University Medical Center Groningen, Center for Rehabilitation, Department of Rehabilitation Medicine, Groningen, The Netherlands *ALLRISC group name is defined in the Acknowledgements at the end of this article.

Objectives: To describe the prevalence of secondary health conditions among persons with long-term spinal cord injury, and the relationship between these secondary health conditions and quality of life.

Design: Multicentre, cross-sectional study.

Subjects: Individuals ($n=282$) with traumatic or non-traumatic spinal cord injury for ≥ 10 years, age at injury 18–35 years, current age 28–65 years, and using a wheelchair.

Methods: Occurrence of 13 secondary health conditions was assessed during a consultation with a rehabilitation physician. Quality of life was measured with the International Spinal Cord Injury Quality of Life Basic Data Set.

Results: Median time since injury was 22.0 years. Median number of secondary health conditions was 4. The most prevalent secondary health conditions were: musculoskeletal pain (63.5%), oedema (38.7%), neuropathic pain (34.1%) and urinary tract infections (33.3%). Only oedema showed a significant association with increasing time since injury. Median Total Quality of Life Basic Data Set score was 7. Musculoskeletal pain, pressure ulcers, problematic spasticity and constipation showed an independent association with quality of life in multiple regression analysis, but in general, these associations were weak.

Conclusion: Secondary health conditions are common among persons with long-term spinal cord injury and the following secondary health conditions were independently associated with lower quality of life: musculoskeletal pain, pressure ulcers, problematic spasticity, and constipation. Minimizing the impact of secondary health conditions should be a priority in the long-term care of persons with spinal cord injury.

Key words: spinal cord injury; health; rehabilitation; quality of life.

J Rehabil Med 2016; 48: 853–860

Correspondence address: Marcel W. M. Post, De Hoogstraat Rehabilitation, Centre of Excellence for Rehabilitation Medicine, PO Box 85238, NL-3508 AE Utrecht, The Netherlands. E-mail address: m.post@dehoogstraat.nl

Accepted Sep 6, 2016; Epub ahead of print Nov 3, 2016

INTRODUCTION

Persons with spinal cord injury (SCI) are likely to experience serious health problems associated with this condition. These secondary health conditions (SHCs) have been defined as “physical or psychological health conditions that are influenced directly or indirectly by the presence of a disability or underlying physical impairment” (1). Examples of SHCs associated with SCI are bladder and bowel disorders, pressure ulcers, spasticity, upper-extremity pain, and cardiovascular and respiratory problems (1). In persons with SCI, the presence of SHCs is associated with a lower life expectancy that remains below that of the general population (2). Therefore, it is essential to gain more knowledge about the long-term consequences of SCI on the health of persons living with SCI.

In a Dutch survey among 454 persons with SCI and a mean time since injury (TSI) of 13.3 years in 2002, a mean of 4.6 SHCs were reported (3). Problems with bladder (71%) and bowel regulation (61%), spasms (57%) and pain (55%) were the most frequently reported SHCs (3). Two studies, reporting on persons living with SCI for at least 20 (4) and 25 years (5), found the same SHCs to be highly prevalent and found pressure ulcers (39% and 56%, respectively) to be a frequent problem. Although exact figures varied between studies, other studies in persons with long-term SCI confirm the frequent occurrence of the aforementioned SHCs (6, 7).

Several demographic- and injury-related characteristics have been associated with the prevalence of SHCs (6, 8–10). A previous review found contractures to be more frequent with longer TSI and that cardiovascular disease, diabetes and respiratory complications were more prevalent in older individuals (8).

Quality of life (QoL) reflects an individual’s overall perception of, and satisfaction with, how things are in his/her life (11). The average QoL in persons with SCI is below that of the general population (12). The presence of SHCs may contribute to the explanation of this lower QoL in persons with SCI. However, the literature on this topic shows diverging results. In 2 studies an association was found between an increasing

number of SHCs and lower QoL (13, 14), but 2 other studies did not find such an association (15, 16). No earlier studies on relationships between specific SHCs and QoL in persons with long-term SCI (mean TSI ≥ 10 years) were found, despite the fact that such knowledge may be helpful in improving long-term care and identifying research priorities.

The aims of this study were therefore to investigate the prevalence of 13 SHCs during the previous 3 months among persons with long-term SCI, stratified for different TSI periods (10–19, 20–29 and ≥ 30 years); and to explore the relationships between these SHCs, TSI and QoL.

METHODS

Design

This study is part of the Dutch multicentre research programme “Active Lifestyle Rehabilitation Interventions in aging Spinal Cord injury (ALLRISC)”, a TSI-stratified cross-sectional study among persons with long-term SCI living in the Netherlands (17). TSI strata were 10–19, 20–29 and ≥ 30 years after SCI. We aimed to include 100 persons per stratum (17).

Participants

Inclusion criteria were: (i) traumatic or non-traumatic SCI with a TSI ≥ 10 years, (ii) age at injury between 18 and 35 years, (iii) current age between 28 and 65 years, and (iv) using a wheelchair (hand-rim propelled or electric wheelchair), at least for longer distances (> 500 m).

These age and age at onset inclusion criteria were applied to limit the confounding effects of age-related co-morbidities and thereby to be better able to study the long-term consequences of SCI. The exclusion criterion was insufficient mastery of the Dutch language to respond to an oral interview or to understand test instructions.

The basis for the power analysis was the aim to detect differences in the prevalence of SHCs between TSI strata. With $\alpha = 0.05$ and power = 0.80, a prevalence of 0.2 can be estimated, with a margin of error of $\pm 4.6\%$. A prevalence difference of 0.2 (0.3 vs 0.5) between 2 TSI strata with 100 participants each would be statistically significant with the same α and power. For regression analysis, this number of 300 participants would allow inclusion of 19 independent variables in the analysis, using the rule of thumb of 15 participants per variable. Therefore, it was aimed to include 100 participants per stratum.

Procedure

Eligible persons were identified in databases from all 8 Dutch rehabilitation centres specializing in SCI rehabilitation. Since we aimed to include 30–35 persons per centre, and expected a response rate of approximately 50%, 62 persons per centre were invited to join the study. If the number of eligible persons allowed it, a random sample was drawn at each centre. If the response was less than 30–35 persons per centre, an additional sample was drawn at that centre.

The study consisted of a 1-day visit to the rehabilitation centre for a check-up, including an extensive medical assessment and physical examination performed by an SCI rehabilitation physician, and an oral interview, and physical tests performed by a research assistant. Two weeks before the visit to the rehabilitation centre, participants were asked to complete a self-report questionnaire.

The research protocol was approved by the Medical Ethics Committee of the University Medical Center Utrecht. All participants gave written informed consent.

Instruments

Secondary health conditions. The occurrence of 13 SHCs was reported as 0 = no occurrence over the past 3 months, 1 = currently present, or

has occurred over the past 3 months. Standardized questions on the type of pain were completed if the participant reported having pain.

Neuropathic pain was defined as at-level or below-level pain, originating from syringomyelia, spinal cord ischaemia or trauma (18). It was further objectified by using the Douleur Neuropathique en 4 Questions (DN4) (19). The DN4 questionnaire consists of 7 items related to symptoms and 3 related to a clinical examination. A total score of 4 or higher out of 10 suggests neuropathic pain. It has shown good test-retest reliability ($\kappa = 0.75$) and a high sensitivity of 93% and specificity of 75% in persons with SCI (20).

Musculoskeletal pain was defined as nociceptive pain originating from bone, joint or muscle trauma or overuse (18).

Pressure ulcers were defined according to the classification of the European Pressure Ulcer Advisory Panel (EPUAP): category I, II, III or IV (21). When a participant indicated that he/she had had a pressure ulcer in the past 3 months, the rehabilitation physician asked further questions on the location and severity of the ulcer. All pressure ulcers, irrespective of category, were included.

Problematic spasticity was scored when a participant indicated that spasticity was present and that it interfered moderately or extensively with activities of daily living.

Autonomic dysreflexia (AD) was defined as a sudden reaction of the autonomic nervous system triggered by a stimulus below the level of the lesion (e.g. bladder distension, UTI), causing an increase in blood pressure in association with other symptoms, such as (i) below the level of the lesion: piloerection, pallor, cold extremities, profuse sweating; and (ii) above the level of the lesion: severe headaches, nasal congestion, flushing of the skin and bradycardia.

Hypotension was checked for by the assessment of symptoms (e.g. light-headedness or fainting).

Oedema was scored when the participant had received relevant treatment (e.g. compression stockings, bandages or diuretic drugs).

Neurogenic heterotopic ossification (NHO) was defined as the presence of bone in soft tissue surrounding paralysed joints, confirmed by radiological examination.

Pneumonia was defined as a lower respiratory tract infection that was treated with antibiotics.

Urinary tract infection (UTI) was defined as a symptomatic infection of the urinary tract, treated with antibiotics. Symptoms had to include 1 or more of the following: fever, onset of urinary incontinence, increased spasticity, malaise, AD, discomfort or pain during urination, gritty particles or mucus in the urine or cloudy urine with increased odour.

Urinary incontinence was operationalized as any involuntary urine leakage, occurring at least once a month. No involuntary urine leakage implied no leakage of urine outside the urinary tract, or a closed urinary collection system.

Faecal incontinence was defined as involuntary loss of faeces occurring at least once a month.

Constipation was scored according to the Rome III criteria for functional constipation (22).

Quality of life. The International SCI QoL Basic Data Set was used for the assessment of QoL (11). It contains 3 items: satisfaction with life as a whole, satisfaction with physical health and satisfaction with psychological health. All 3 items are self-rated on a 0–10 scale with a time frame of the past 4 weeks, with 0 = completely dissatisfied and 10 = completely satisfied (11). The Total QoL Basic Data Set Score (Total QoL Score) is the mean of the 3 item scores.

Details on the validity of the International SCI QoL Basic Data Set items are reported elsewhere (23). The 3 items showed generally strong inter-correlations and the total QoL score showed good internal consistency (Cronbach's $\alpha = 0.81$). The 3 items and the total score were strongly correlated with scores on reference measures (23).

Potential confounders (demographic and injury-related characteristics). Potential confounders in the relationship between SHCs and QoL were identified from previous studies (13, 16, 24, 25).

Demographic variables were part of the self-report questionnaire and included age, sex, nationality (Dutch, other), married/stable relationship (yes, no), having children (yes, no), level of education (high/low was defined as with/without college or university degree) and employment (paid work for at least 1 h per week).

The International Standards for Neurological Classification of SCI were used to assess lesion characteristics (26). Tetraplegia was defined as a lesion at or above the first thoracic segment and paraplegia as a lesion below the first thoracic segment. A complete lesion was diagnosed in the absence of motor and sensory function in the sacral segments, i.e. American Spinal Injury Association (ASIA) Impairment Scale (AIS) A. Grades B, C and D on the scale were considered to represent an incomplete lesion (26). TSI and aetiology (traumatic vs non-traumatic) were also recorded.

The Spinal Cord Independence Measure III (SCIM-III) was used to assess functional independence. The total score range is 0 to 100 and higher scores indicate higher levels of independence in daily activities (27).

Statistical analysis

Descriptive analyses were performed to describe demographic and injury-related characteristics, frequency of SHCs, and QoL scores.

χ^2 tests were used to explore differences in the proportions of participants with certain SHCs between the 3 TSI strata. When a statistically significant effect ($p < 0.05$) was found, *post-hoc* tests were performed to explore between which of the 3 TSI strata the difference existed. To decrease the risk of committing a type I error in these *post-hoc* analyses, a Bonferroni correction ($p = 0.05/3 = 0.017$) was applied.

Continuous variables were assessed for normality. Two of the 4 QoL scores (satisfaction with life as a whole and satisfaction with psychological health), TSI and functional independence scores showed skewed score distributions. Therefore, the Kruskal–Wallis test was used to analyse differences between the 3 different TSI groups on the continuous variables. The Mann–Whitney *U* test was used to test for differences between 2 independent groups (the SHCs as dichotomous variables) on TSI as a continuous variable and on the QoL scores. Effect sizes were calculated from the Mann–Whitney *U* test statistics as follows: $r = Z\text{-value}/\text{square root of } n$ ($n = \text{total number of cases}$). Effect sizes were interpreted using Cohen criteria: 0.10–0.29 small effect; 0.30–0.49 medium effect; 0.50–1.0 large effect.

Bivariate linear regression was performed to explore the association between a single possible determinant on the Total QoL Score. Standard

multiple linear regression was used to assess independent associations between SHCs and the Total QoL Score, corrected for the potential confounding effect of demographic and injury-related characteristics. Preliminary analyses were performed to ensure the assumptions for multiple regression (normality, linearity, homoscedasticity and no multicollinearity) were not violated. For the multiple regression analysis the rule of thumb of 15 participants per determinant was used, allowing the use of 17 determinants. Therefore, only variables with a *p*-value below 0.10 in the bivariate regression were entered in the multiple regression analysis.

We dealt with the missing data by using pairwise deletion of cases with missing values.

All analyses were performed using the SPSS statistical software (SPSS 21.0 for Windows; IBM Corp.; Armonk, New York).

RESULTS

Participant characteristics

Between November 2011 and February 2014 a total of 566 persons were invited to participate in the study, 292 of whom were ultimately included. The main reasons for non-participation were: a large travel distance, unwillingness, too busy with daily life, and health issues. After the inclusion procedure there were 10 participants who, in retrospect, did not meet all the inclusion criteria and were therefore excluded from the analyses. A total of 261 participants (92.6%) completed all QoL questions. The characteristics of the participants ($n = 282$) are described in Table I. We were not able to perform a non-response analysis, since not all of the participating rehabilitation centres could provide us with the required information concerning the non-respondents.

Secondary health conditions

A median of 4 (interquartile range (IQR) 2–5) SHCs were reported over the previous 3 months. Furthermore, 98.5% of the participants had had at least one SHC.

Table I. Participant's characteristics ($n = 282$)

	Total	TSI 10–19 years ($n = 107$)	TSI 20–29 years ($n = 96$)	TSI ≥ 30 years ($n = 79$)	<i>p</i> -value
Age, years, median (IQR)	47.8 (41.6–55.0)	40.3 (36.6–44.5)	48.0 (44.0–52.3)	59.0 (53.9–63.1)	<0.001
Time since injury, years, median (IQR)	22.0 (16.8–30.3)	–	–	–	–
Sex; male, %	74	72	80	70	0.229
Nationality, Dutch*, %	96	94	98	97	0.315
Cause, traumatic, %	91	94	92	87	0.231
Level, tetraplegia, %	41	42	43	39	0.896
ASIA Impairment Scale, %					0.170
A	69	74	70	59	
B	14	11	10	20	
C	10	10	10	8	
D	8	5	8	13	
Functional independence (SCIM-III score), median (IQR)**	64.0 (43.0–69.0)	66 (44.5–68.0)	64.5 (36.5–69.25)	62.5 (45.75–68.0)	0.627
Relationship, married/stable relationship*, %	61	57	64	62	0.586
Children, ≥ 1 child*, %	47	43	48	53	0.445
Level of education, college/university*, %	44	45	48	40	0.549
Employment, paid work ≥ 1 h/week*, %	39	48	39	28	0.023

* $n = 268$ participants who completed the self-report questionnaire.

** $n = 277$ participants who completed the SCIM-III questionnaire.

Significant values are shown in bold.

ASIA: American Spinal Injury Association; IQR: interquartile range; SCIM-III: Spinal Cord Independence Measure III; TSI: time since injury.

Table II. Prevalence of secondary health conditions (SHCs)

Secondary health conditions	Overall group (<i>n</i> =282) % (95% CI)	TSI 10–19 years (<i>n</i> =107) % (95% CI)	TSI 20–29 years (<i>n</i> =96) % (95% CI)	TSI ≥30 years (<i>n</i> =79) % (95% CI)	<i>p</i> -value for between group difference	<i>p</i> -value for TSI as a continuous variable
Neuropathic pain	34.1 (0.27–0.38)	35.5 (0.2–0.44)	34.0 (0.23–0.41)	32.1 (0.21–0.41)	0.887	0.660
Musculoskeletal pain	63.5 (0.58–0.69)	65.4 (0.56–0.74)	51.0 (0.41–0.61)	75.9 (0.66–0.85)	0.003^c	0.197
Pressure ulcers	29.4 (0.24–0.35)	27.1 (0.19–0.36)	30.2 (0.21–0.39)	31.6 (0.21–0.42)	0.781	0.369
Problematic spasticity	23.8 (0.19–0.29)	28.0 (0.19–0.37)	26.0 (0.17–0.35)	15.2 (0.07–0.23)	0.102	0.036
Autonomic dysreflexia	19.1 (0.15–0.24)	30.8 (0.22–0.40)	12.5 (0.06–0.19)	11.4 (0.04–0.18)	0.000^{a,b}	0.001
Hypotension	20.6 (0.16–0.25)	24.3 (0.16–0.32)	22.9 (0.14–0.31)	12.7 (0.05–0.20)	0.119	0.089
Oedema	38.7 (0.33–0.44)	29.0 (0.20–0.38)	41.7 (0.32–0.52)	48.1 (0.37–0.59)	0.023^b	0.001
NHO	24.1 (0.19–0.29)	20.6 (0.13–0.28)	29.2 (0.20–0.38)	22.8 (0.14–0.32)	0.341	0.469
Pneumonia*	5.1 (0.03–0.08)	9.4 (0.04–0.15)	2.2 (0.00–0.05)	2.7 (0.00–0.06)	0.036 ^d	0.035
Urinary tract infection	33.3 (0.28–0.39)	30.8 (0.22–0.40)	36.5 (0.27–0.46)	32.9 (0.23–0.43)	0.695	0.825
Urinary incontinence	27.0 (0.22–0.32)	26.2 (0.18–0.35)	27.1 (0.18–0.36)	27.8 (0.18–0.38)	0.967	0.778
Faecal incontinence**	16.0 (0.12–0.20)	17.8 (0.11–0.25)	18.9 (0.11–0.27)	10.1 (0.03–0.17)	0.236	0.489
Constipation	25.2 (0.20–0.30)	31.8 (0.23–0.41)	19.8 (0.12–0.28)	22.8 (0.14–0.32)	0.123	0.115

*Total of 1 missing in 20–29 years group; **total of 9 missing: 1 in 10–19 years group, 3 in 20–29 years group, 5 in ≥30 years group.

^aSignificance between TSI 10–19 years and 20–29 years groups; ^bsignificance between TSI 10–19 years and ≥30 years groups; ^csignificance between TSI 20–29 years and ≥30 years groups; ^dno significance between groups after Bonferroni correction ($p > 0.017$).

Significant values are shown in bold.

CI: confidence interval; NHO: neurogenic heterotopic ossification; TSI: time since injury.

The prevalence of SHCs in each TSI stratum is displayed in Table II. In general, the hypothesis that the prevalence of SHCs would increase with increasing TSI could not be confirmed. Musculoskeletal pain was the most frequently reported SHC and was more common in the TSI ≥30 years group, compared with the TSI 20–29 years group. Oedema was more common in the TSI ≥30 years group, compared with the TSI 10–19 years group. AD was less common in the TSI 20–29 years and ≥30 years group, compared with the TSI 10–19 years group. Pneumonia was also less common in the longer TSI groups; however, this was not statistically significant after the Bonferroni correction.

Quality of life

Table III shows the QoL scores stratified for TSI. No significant differences were observed in QoL scores between TSI strata.

Table IV displays the effect sizes for the differences in QoL scores for the different SHCs, tested with the Mann-Whitney *U* Test. In general, the effect sizes were small.

Bivariate regression

Results of all regression analyses are summarized in Table V. SHCs that were negatively associated ($p < 0.05$) with the Total QoL Score were musculoskeletal pain, pressure ulcers, problematic spasticity, hypotension, UTI and constipation. AD showed

a negative association with QoL at $p < 0.10$. Participant characteristics that were found to have a positive bivariate association ($p < 0.05$) with Total QoL Basic Data Set Score were: employment, having a stable relationship, and higher functional independence.

Standard multiple regression

Four out of 7 included SHCs showed a unique association with lower QoL (Table V). These were: musculoskeletal pain, pressure ulcers, problematic spasticity and constipation. Participant characteristics that had an association with higher QoL were: having a stable relationship, and employment. The multiple regression model explained 23.0% of the variance in Total QoL Basic Data Set Scores (Table V), of which 12.6% was explained by the included SHCs and 10.4% was explained by the included participant characteristics.

DISCUSSION

This study shows that SHCs are common among persons with long-term SCI. Only one SHC showed a significant association with increasing TSI. Four SHCs (musculoskeletal pain, pressure ulcers, problematic spasticity and constipation) appeared to have an independent association with QoL, but, in general, these associations were weak.

Table III. Quality of life scores

Quality of life scores	Overall group Median (IQR)	TSI 10–19 years Median (IQR)	TSI 20–29 years Median (IQR)	TSI ≥30 years Median (IQR)	<i>p</i> -value
Satisfaction with life as a whole (<i>n</i> =263)	7 (6–8)	7 (6–8)	7 (6–8)	7 (6–8)	0.910
Satisfaction with physical health (<i>n</i> =264)	6 (4–7)	6 (4–7.5)	6 (4–7)	6 (5–7)	0.508
Satisfaction with psychological health (<i>n</i> =262)	7 (6–8)	7 (6–8)	8 (7–9)	7 (6–8)	0.256
Total QoL Basic Data Set Score (<i>n</i> =261)	7.0 (5.7–7.7)	7.0 (5.3–7.7)	7.0 (5.7–7.7)	6.7 (5.7–8.0)	0.981

IQR: interquartile range; QoL: quality of life; TSI: time since injury; Scores for all 4 quality of life variables range from 0 to 10, with 0=completely dissatisfied and 10=completely satisfied.

Table IV. Effect sizes ^afor the differences in quality of life scores for the different secondary health conditions tested with the Mann–Whitney U test

Secondary health conditions	Satisfaction with life as a whole (n=263)	Satisfaction with physical health (n=264)	Satisfaction with psychological health (n=262)	Total QoL Basic Data Set Score (n=261)
Neuropathic pain	0.07	0.00	0.00	0.03
Musculoskeletal pain	0.08	0.12*	0.14*	0.13*
Pressure ulcer	0.15*	0.16*	0.16*	0.17**
Problematic spasticity	0.16*	0.19**	0.13*	0.20**
Autonomic dysreflexia	0.10	0.09	0.03	0.07
Hypotension	0.13*	0.14*	0.10	0.14*
Oedema	0.03	0.04	0.06	0.03
NHO	0.03	0.01	0.00	0.00
Pneumonia	0.04	0.02	0.06	0.05
Urinary tract infection	0.09	0.20**	0.03	0.12
Urinary incontinence	0.07	0.04	0.05	0.07
Faecal incontinence	0.03	0.14*	0.02	0.08
Constipation	0.13*	0.15*	0.17**	0.17**

* $p < 0.05$; ** $p < 0.01$. ^aCalculation of the effect size of Mann–Whitney U test: $r = Z\text{-value}/\text{square root of } n$.

NHO: neurogenic heterotopic ossification; QoL: quality of life.

Prevalence of secondary health conditions

The number of SHCs experienced by the participants was comparable to findings of other studies. A previous study found that only 4.4% of persons with a SCI for at least 10 years were free from SHCs at the time of routine physical examination (28). Another study with a mean TSI of 19 years found a mean of 4.1 SHCs over the past year (6).

The expected increase in prevalence of SHCs with longer TSI was observed only for oedema. A possible explanation for

the absence of this association for other SHCs is the so-called “survivor effect”, meaning that those with better outcomes are more likely to survive and participate in a study (29).

Comparing frequencies of specific SHCs across studies is complicated, as study populations and definitions of SHCs differ. Musculoskeletal pain was highly prevalent. The overall prevalence of 63.5% is somewhat higher than the 50.5% found by Wollaars et al. (30). This difference might be explained by Wollaars et al.’s shorter mean TSI of 11.8 years and the fact

Table V. Regression analyses, Total QoL Basic Data Set Score (n = 261)

Variables entered	Bivariate regression			Standard multiple regression		
	B* (SE)	beta*	p-value	B (SE)	beta	p-value
Age (continuous)	−0.006 (0.012)	−0.029	0.643			
Sex, male	0.371 (0.241)	0.095	0.124			
TSI (continuous)	0.007 (0.012)	0.035	0.572			
Cause, traumatic	0.103 (0.373)	0.017	0.782			
Level, tetraplegia	−0.153 (.215)	−0.044	0.479			
Complete lesion	0.135 (0.229)	0.037	0.555			
Functional independence (continuous)	0.018 (0.006)	0.196	0.002	0.010 (0.005)	0.112	0.061
Stable relationship	0.564 (0.214)	0.161	0.009	0.566 (0.199)	0.162	0.005
Children	−0.033 (0.212)	−0.010	0.878			
Education, high	0.276 (0.213)	0.080	0.196			
Employment	0.855 (0.210)	0.245	0.000	0.664 (0.202)	0.190	0.001
Neuropathic pain	0.084 (0.223)	0.023	0.707			
Musculoskeletal pain	−0.468 (0.218)	−0.132	0.033	−0.488 (.200)	−0.138	0.016
Pressure ulcer	−0.708 (0.228)	−0.189	0.002	−0.687 (0.215)	−0.184	0.002
Problematic spasticity	−0.744 (.245)	−0.186	0.003	−0.788 (0.232)	−0.197	0.001
Autonomic dysreflexia	−0.475 (0.268)	−0.110	0.077	−0.050 (0.265)	−0.012	0.850
Hypotension	−0.747 (0.258)	−0.177	0.004	−0.363 (0.254)	−0.086	0.155
Oedema	−0.010 (0.218)	−0.003	0.964			
NHO	−0.067 (0.248)	−0.017	0.787			
Pneumonia	0.310 (0.489)	0.04	0.526			
Urinary tract infection	−0.470 (0.223)	−0.130	0.036	−0.248 (0.213)	−0.069	0.246
Urinary incontinence	0.199 (0.239)	0.052	0.404			
Faecal incontinence	−0.416 (0.288)	−0.089	0.150			
Constipation	−0.627 (0.241)	−0.159	0.010	−0.514 (0.225)	−0.131	0.023
				R	R square	
				0.480	0.230	

*Positive B and beta values signify an increase in Total QoL Basic Data Set Score, negative values a decrease.

NHO: neurogenic heterotopic ossification; QoL: quality of life; TSI: time since injury; SE: standard error.

that only chronic pain (> 6 months duration) was measured. A previous review also reported the prevalence of only chronic musculoskeletal pain (≥ 3 months duration) in persons with SCI (TSI range 3–51 years) and found prevalence ranges of 28.4–59.0%, which is still lower compared with our overall prevalence (31).

The observed prevalence of neuropathic pain was low compared with other studies in the literature. Previous studies in persons with a mean TSI of at least 10 years showed percentages ranging from 56% to 65% (7, 30). The highest prevalence was found in a study in which neuropathic pain was assessed over the past year (7). Wollaars et al. (30) also measured chronic neuropathic pain (> 6 months duration), potentially partially explaining the differences with our study. Another possible explanation is that there seems to be a positive correlation between an advanced age at injury and the onset of neuropathic pain. Compared with previous studies on neuropathic pain, our participants were relatively young at the time of injury, between 18 and 35 years old, potentially explaining our lower observed prevalence. Furthermore, none of these previous studies have used a screening tool that has been validated for screening neuropathic pain in persons with SCI, while in our study the DN4 questionnaire was used, which has been described as the most suitable screening tool for neuropathic pain in persons with SCI (20).

The prevalence of pressure ulcers was comparable to previous studies in long-term SCI. Prevalences between 23.3% (TSI 10 years) and 29.4% (TSI 20 years) at the time of evaluation (32) and 38.7% (TSI > 20 years) over the past 3 years (4) have been reported. The prevalence in our study might be an underestimation. Since bed rest is a common treatment for pressure ulcers, persons with pressure ulcers might have been prohibited from study participation, which required travelling to the rehabilitation centre. The increasing prevalence with longer TSI in some (28, 33), but not all (8) previous studies, was not seen in the current study.

Secondary health conditions and quality of life

Study participants scored their QoL as rather satisfying. This is in accordance with previous studies (12, 34). Overall, the associations between SHCs and QoL were surprisingly weak. There might be 2 explanations. First, with a median of 4 SHCs over the past 3 months, it is reasonable to assume that participants have experienced SHCs regularly over the previous years, have accommodated to their presence and that SHCs thereby no longer substantially influence self-evaluations of QoL. In the literature this process of adaptation in persons with a chronic disease is known as “response shift” (35).

Secondly, it could be that SHCs that occurred and have been overcome early in the 3-month period, no longer influenced QoL, which was measured over the previous 4 weeks.

Notwithstanding this, 4 SHCs did relate with lower QoL. A number of previous articles did show a negative association between pain and QoL after SCI (24, 30, 36). As expected, musculoskeletal pain was negatively associated with QoL in this study; however, neuropathic pain was not. This may be due to

the definition, which did not include a severity nor a frequency criterion. Perhaps we would have found an association with QoL if we had also measured the severity of the neuropathic pain. Problematic spasticity influenced QoL negatively. Two previous studies found an association between spasticity and lower QoL in persons with SCI (24, 37), while another did not (38). Only one of these studies included interference with daily life in the definition of spasticity (37). It is known that spasticity can be experienced as negative (e.g. hampering daily activities) and positive (e.g. facilitating transfers) and that context is important in this difference. Having added “problematic” to the definition might be the reason an association was found in this study, but not in all others.

The negative effect of pressure ulcers on QoL is in accordance with some (24), but not all previous studies (39). Treatment for pressure ulcers in the Netherlands includes full bed rest and sometimes surgical interventions, and is very likely to impact on QoL.

Constipation was negatively associated with QoL in this study. As far as we know, this relationship has not been studied previously in the SCI population. A recent study among persons with SCI did show that constipation is associated with an increased risk of not participating in many daily activities (40). The authors suggested that this might be because constipation management can be time-consuming and subsequently have a disruptive effect on daily schedules (40). Participation restriction might be one explanatory link between constipation and lower QoL in persons with SCI.

Study strengths

To the best of our knowledge, this is one of the few studies specifically addressing SHCs in persons with long-term SCI (≥ 10 years) and the first international study to relate SHCs with QoL in this population. Furthermore, unlike other studies that measured self-reported SHCs using questionnaires (3, 7, 10, 30) or telephone interviews (4, 6), SHCs were assessed in a more objective manner by a consultation with a rehabilitation physician in this study. Lastly, the restriction to persons aged 18–35 years at SCI onset and current age below 65 years minimized the confounding effect of age at injury and current age, respectively.

Study limitations

This study has some limitations. First, the cross-sectional design limits the possibilities to interpret associations between TSI and age. As a consequence of the study design, causal conclusions on the association with QoL also cannot be drawn. Secondly, the inclusion target of 100 persons with a SCI for at least 30 years was not reached. Thirdly, recall errors might have taken place, although the restriction of the time-frame of the occurrence of SHCs to the previous 3 months probably limits the extent of this problem. As mentioned previously, the prevalence of pressure ulcers might be an underestimation of the true extent. Fourthly, as this is an explorative study we have chosen not to adjust the *p*-value for multiple comparisons concerning our analyses with the 13 SHCs. Therefore, the risk of finding a false-positive result by chance cannot be ruled out. Fifthly, we did

not report on concomitant diseases, although these might also impact the presence of certain SHCs and QoL. Finally, due to the inclusion criteria, our study sample predominantly consisted of participants with a traumatic and complete SCI who obtained their SCI at a relatively young age. This should be kept in mind when interpreting the study results, since some SHCs, such as pneumonia and AD, are more common in certain SCI patient groups. Another limitation concerning the representativeness of the study sample was the fact that we had no information regarding the comparability between participants and non-participants for the total group nor for the 3 TSI groups.

Clinical implications

It is important that professional caregivers and healthcare policymakers are aware of the high prevalence of SHCs among persons with long-term SCI. Since most SHCs are at least partially preventable, patient education and adequate self-management should become a focus point. For unpreventable conditions, such as neuropathic pain, adequate treatment plans should be made together with the patient. Since musculoskeletal pain, pressure ulcers, problematic spasticity and constipation are associated with lower QoL, special attention should be paid to these in terms of prevention, early diagnosis and treatment.

In the Netherlands a substantial part of the complex care for persons with long-term SCI is provided by general practitioners. Centralizing care for persons with long-term SCI in specialized rehabilitation centres and the development of national guidelines for systematic follow-up are possible strategies to enhance the quality of long-term care for persons with SCI that need to be evaluated for their ability to decrease the occurrence of SHCs.

Conclusion

SHCs are very frequent among persons with long-term SCI. The following 4 SHCs showed independent weak associations with QoL: musculoskeletal pain, pressure ulcers, problematic spasticity and constipation.

ACKNOWLEDGEMENTS

The authors would like to thank all ALLRISC research assistants and SCI rehabilitation physicians for collecting all the data and the following participating Dutch rehabilitation centres: Rehabilitation Centre De Hoogstraat (Utrecht), Reade Centre for Rehabilitation (Amsterdam); Rehabilitation Centre Het Roessingh (Enschede); Adelante Rehabilitation Centre (Hoensbroek); Sint Maartenskliniek (Nijmegen); University Medical Centre Groningen, Centre for Rehabilitation-location Beatruxoord (Haren); Rehabilitation Centre Heliomare (Wijk aan Zee); and Rijndam Rehabilitation Centre (Rotterdam).

ALLRISC group name: Luc as H.V. van der Woude^{1,2}, PhD, Sonja de Groot^{1,3}, PhD, Thomas W.J. Janssen^{3,4}, PhD, Hans Arjan J.T. Bakkum⁴, PhD, Jan W. van der Scheer¹, PhD, Hedwig Kooijmans⁵, MSc, Bussmann⁵, PhD, Janneke Stolwijk⁶, PhD, MD, Maurits Sloots⁷, PhD, OT, Hennie Rijkens⁸, PT, Willemijn X. Faber⁹, MD, Hans J. Slootman⁹, MD, Linda Valent⁹, PhD OT, Marijke Schuitemaker¹⁰, PT, Marga Tepper¹, MD, Ferry Woldring¹, PT, Helma M.H. Bongers-Janssen⁸, MD, Sandra Slangen¹¹, PT, Mia Wynants¹¹, PT, Dorien Spijkerman¹², MD, Rogier Broeksteeg¹², and Peter Luthart⁶, PT

From the ¹Center for Human Movement Sciences and ²University of Groningen, University Medical Center Groningen, Groningen, ³Amster-

dam Rehabilitation Research Center Reade, ⁴MOVE Research Institute Amsterdam, Faculty of Human Movement Sciences, VU University Amsterdam, ⁵Department of Rehabilitation Medicine and Physical Therapy, Erasmus MC University Medical Center, Rotterdam, ⁶De Hoogstraat Rehabilitation, Utrecht, ⁷Amsterdam Rehabilitation Research Center I Reade, Amsterdam, ⁸Sint Maartenskliniek, Nijmegen, ⁹Heliomare Rehabilitation Centre, Wijk aan Zee, ¹⁰Roessingh Rehabilitation Centre, Enschede, ¹¹Adelante Rehabilitation Centre, Hoensbroek and ¹²Rijndam Rehabilitation Centre, Rotterdam, The Netherlands.

ALLRISC is sponsored by "Fonds NutsOHRA" under the responsibility of the Netherlands Organisation for Health Research and Development (www.ZonMw.nl), project number 89000006.

REFERENCES

1. Jensen MP, Molton IR, Groah SL, Campbell ML, Charlifue S, Chiodo A, et al. Secondary health conditions in individuals aging with SCI: terminology, concepts and analytic approaches. *Spinal Cord* 2012; 50: 373–378.
2. Krause JS, Saunders LL. Health, secondary conditions, and life expectancy after spinal cord injury. *Arch Phys Med Rehabil* 2011; 92: 1770–1775.
3. Bloemen-Vrencken JH, Post MW, Hendriks JM, De Reus EC, De Witte LP. Health problems of persons with spinal cord injury living in the Netherlands. *Disabil Rehabil* 2005; 27: 1381–1389.
4. Liem NR, McColl MA, King W, Smith KM. Aging with a spinal cord injury: factors associated with the need for more help with activities of daily living. *Arch Phys Med Rehabil* 2004; 85: 1567–1577.
5. Werhagen L, Aito S, Tucci L, Strayer J, Hultling C. 25 years or more after spinal cord injury: clinical conditions of individuals in the Florence and Stockholm areas. *Spinal Cord* 2012; 50: 243–246.
6. Hitzig SL, Campbell KA, McGillivray CF, Boschen KA, Craven BC. Understanding age effects associated with changes in secondary health conditions in a Canadian spinal cord injury cohort. *Spinal Cord* 2010; 48: 330–335.
7. Noreau L, Noonan VK, Cobb J, Leblond J, Dumont FS. Spinal cord injury community survey: a national, comprehensive study to portray the lives of Canadians with spinal cord injury. *Top Spinal Cord Inj Rehabil* 2014; 20: 249–264.
8. Jensen MP, Truitt AR, Schomer KG, Yorkston KM, Baylor C, Molton IR. Frequency and age effects of secondary health conditions in individuals with spinal cord injury: a scoping review. *Spinal Cord* 2013; 51: 882–892.
9. Adriaansen JJ, Post MW, de Groot S, van Asbeck FW, Stolwijk-Swüste JM, Tepper M, et al. Secondary health conditions in persons with spinal cord injury: a longitudinal study from one to five years post-discharge. *J Rehabil Med* 2013; 45: 1016–1022.
10. Saunders LL, Clarke A, Tate DG, Forchheimer M, Krause JS. Lifetime prevalence of chronic health conditions among persons with spinal cord injury. *Arch Phys Med Rehabil* 2015; 96: 673–679.
11. Charlifue S, Post MW, Biering-Sørensen F, Catz A, Dijkers M, Geyh S, et al. International Spinal Cord Injury Quality of Life Basic Data Set. *Spinal Cord* 2012; 50: 672–675.
12. Post MW, van Leeuwen CM. Psychosocial issues in spinal cord injury: a review. *Spinal Cord* 2012; 50: 382–389.
13. van Koppenhagen CF, Post MW, van der Woude LH, de Groot S, de Witte LP, van Asbeck FW, et al. Recovery of life satisfaction in persons with spinal cord injury during inpatient rehabilitation. *Am J Phys Med Rehabil* 2009; 88: 887–895.
14. Barker RN, Kendall MD, Amstern DI, Pershouse KJ, Haines TP, Kuipers P. The relationship between quality of life and disability across the lifespan for people with spinal cord injury. *Spinal Cord* 2009; 47: 149–155.
15. Tonack M, Hitzig SL, Craven BC, Campbell KA, Boschen KA, McGillivray CF. Predicting life satisfaction after spinal cord injury

- in a Canadian sample. *Spinal Cord* 2008; 46: 380–385.
16. van Leeuwen CM, Post MW, van Asbeck FW, Bongers-Janssen HM, van der Woude LH, et al. Life satisfaction in people with spinal cord injury during the first five years after discharge from inpatient rehabilitation. *Disabil Rehabil* 2012; 34: 76–83.
 17. Adriaansen JJ, van Asbeck FW, Lindeman E, van der Woude LH, de Groot S, Post MW. Secondary health conditions in persons with a spinal cord injury for at least 10 years: design of a comprehensive long-term cross-sectional study. *Disabil Rehabil* 2013; 35: 1104–1110.
 18. Burchiel KJ, Hsu FP. Pain and spasticity after spinal cord injury: mechanisms and treatment. *Spine* 2001; 26: S146–S160.
 19. Bouhassira D, Attal N, Alchaar H, Boureau F, Brochet B, Bruxelle J, et al. Comparison of pain syndromes associated with nervous or somatic lesions and development of a new neuropathic pain diagnostic questionnaire (DN4-). *Pain* 2005; 114: 29–36.
 20. Hallström H, Norrbrink C. Screening tools for neuropathic pain: can they be of use in individuals with spinal cord injury? *Pain* 2011; 152: 772–779.
 21. European Pressure Ulcer Advisory Panel and National Pressure Ulcer Advisory Panel. Prevention and treatment of pressure ulcers: clinical practice guideline. Washington DC: National Pressure Ulcer Advisory Panel, 2009.
 22. Drossman DA, Dumitrascu DL. Rome III: New standard for functional gastrointestinal disorders. *J Gastrointest Liver Dis* 2006; 15: 237–241.
 23. Post, MWM, Adriaansen JJE, Charlifue S, Biering-Sørensen, van Asbeck FWA. Good validity of the International Spinal Cord Injury Basic Quality of Life Data Set. *Spinal Cord* 2016; 54: 314–318.
 24. Post MW, de Witte LP, van Asbeck FW, van Dijk AJ, Schrijvers AJ. Predictors of health status and life satisfaction in spinal cord injury. *Arch Phys Med Rehabil* 1998; 79: 395–401.
 25. Dijkers MP. Quality of life of individuals with spinal cord injury: a review of conceptualization, measurement, and research findings. *J Rehabil Res Dev* 2005; 42: 87–110.
 26. Kirshblum SC, Burns SP, Biering-Sorensen F, Donovan W, Graves DE, Jha A, et al. International standards for neurological classification of spinal cord injury (Revised 2011). *J Spinal Cord Med* 2011; 34: 535–546.
 27. Catz A, Itzkovich M, Tesio L, Biering-Sorensen F, Weeks C, Laramie MT, et al. A multicenter international study on the Spinal Cord Independence Measure, version III: Rasch psychometric validation. *Spinal Cord* 2007; 45: 275–291.
 28. Anson CA, Shepherd C. Incidence of secondary complications in spinal cord injury. *Int J Rehabil Res* 1996; 19: 55–66.
 29. Krause JS, Bozard JL. Natural course of life changes after spinal cord injury: a 35-year longitudinal study. *Spinal Cord* 2012; 50: 227–231.
 30. Wollaars MM, Post MW, van Asbeck FW, Brand N. Spinal cord injury pain: the influence of psychologic factors and impact on quality of life. *Clin J Pain* 2007; 23: 383–391.
 31. Michailidou C, Marston L, De Souza LH, Sutherland I. A systematic review of the prevalence of musculoskeletal pain, back and low back pain in people with spinal cord injury. *Disabil Rehabil* 2014; 36: 705–715.
 32. McKinley WO, Jackson AB, Cardenas DD, DeVivo MJ. Long-term medical complications after traumatic spinal cord injury: a regional model systems analysis. *Arch Phys Med Rehabil* 1999; 80: 1402–1410.
 33. Charlifue S, Lammertse DP, Adkins RH. Aging with spinal cord injury: changes in selected health indices and life satisfaction. *Arch Phys Med Rehabil* 2004; 85: 1848–1853.
 34. Tate D, Forchheimer M. Review of cross-cultural issues related to quality of life after spinal cord injury. *Top Spinal Cord Inj Rehabil* 2014; 20: 181–190.
 35. Sprangers MA, Schwartz CE. Integrating response shift into health-related quality of life research: a theoretical model. *Soc Sci Med* 1999; 48: 1507–1515.
 36. Sakakibara BM, Hitzig SL, Miller WC, Eng JJ, SCIRE Research Team. An evidence-based review on the influence of aging with a spinal cord injury on subjective quality of life. *Spinal Cord* 2012; 50: 570–578.
 37. Westerkam D, Saunders LL, Krause JS. Association of spasticity and life satisfaction after spinal cord injury. *Spinal Cord* 2011; 49: 990–994.
 38. Noonan VK, Kopec JA, Zhang H, Dvorak MF. Impact of associated conditions resulting from spinal cord injury on health status and quality of life in people with traumatic central cord syndrome. *Arch Phys Med Rehabil* 2008; 89: 1074–1082.
 39. Sweet SN, Noreau L, Leblond J, Dumont FS. Understanding quality of life in adults with spinal cord injury via SCI related needs and secondary complications. *Top Spinal Cord Inj Rehabil* 2014; 20: 321–328.
 40. Cobb J, Dumont FS, Leblond J, Park SE, Noonan VK, Noreau L. An exploratory analysis of the potential association between SCI secondary health conditions and daily activities. *Top Spinal Cord Inj Rehabil* 2014; 20: 277–288.